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Benefits of a Family-Directed Services Model

A family-directed service system delivery model would give parents of children with developmental disabilities more choice and flexibility in purchasing the services and supports their children need. These services would help the family to support their child at home and in the community to help ensure inclusion to the greatest extent possible. It would allow for more efficient and effective use of services, especially important with the current focus on state Medicaid budgets and activities that would affect possible savings.

With an individualized budget a family can plan a year of therapy, support, services and goods that would enable their child to live as full and inclusive a life as possible. The flexibility in this model would allow parents to choose services that best meet their child's specific needs because of their disability and arrange for those services in a way that best fits their family's needs as well.

For example: a family may choose to use funding for physical therapy in an integrated setting like hippotherapy (horseback riding to improve trunk stability and balance) or adaptive swimming lessons with one-on-one support rather than in a clinical setting. A family may choose to purchase developmental therapy for their child for support during classes at the local community center or specialized child care for a time when they need to be away from home. Specialized, experienced staff is often needed to provide swimming lessons or other recreational support to a child with a developmental disability. Staff could be hired that would provide the support a child needs to attend an integrated preschool or participate in spring break camps and summer camps with their peers. Parents would be able to choose traditional service providers or non-traditional providers that have the skills and experience desired by the family.

Like My Voice My Choice, the self-directed service option recently available to adults with developmental disabilities, family-directed services would allow for creative and innovative ways to access services that the current system does not, while still maintaining accountability required by the Center for Medicare and Medicaid Services (CMS).

A possible family story:

Mary and John's young daughter, Sarah, has autism. Sarah receives Medicaid services for support at home, school and in the community through the Medicaid for Certain Disabled Children option. Mary and John must work with a registered service provider agency to get developmental therapy for their daughter after school. The agency provides different support staff to work with Sarah each week to practice communication skills, learn independent living skills and appropriate behaviors for public places. Sarah receives occupational therapy and speech and language therapy at the provider's facility twice each week and physical therapy at a hospital facility each Thursday. Although Sarah has been benefiting from the services provided by the agency, Mary and John must often teach new staff about their daughter and staff changes cause Sarah to feel anxious and upset. The facility where Sarah gets physical therapy is a long drive from the family home and the repetitive nature of the exercises causes Sarah to become very resistant to therapy sessions. In addition, the family's lifestyle and daily/weekly schedule must be coordinated with service providers' schedules for Sarah's services and they are rarely together for family activities.

After choosing a family-directed service model, Sarah's parents have interviewed and hired two support staff that Sarah has known for a while and with whom she is very comfortable. The staff provides support to Sarah in the community at a dance class, and horseback riding lessons in which Sarah is very enthusiastic and she receives the benefits of physical therapy. Mary and John continue to access speech/language therapy from the service provider agency once each week. The speech language pathologist has provided a plan with guidelines for support staff to help Sarah with communication skills in the community. She has recently been enrolled in a drama club where, with the help of support staff, she is able to practice speech and communication skills while interacting with her peers. The family has encouraged and supported their hired staff to learn new research-based techniques to provide positive behavioral support and help children with autism interact socially. Sarah has been making great progress through experiences in the community and with the support from her family and staff. In addition, the family is able to schedule more of their time to be spent together.